# National CAHPS® Benchmarking Database

#### **DATA RELEASE POLICY**

#### Introduction

The National CAHPS® Benchmarking Database (NCBD) is the national repository for data from the CAHPS® family of surveys. The NCBD was initiated in 1998 to support benchmarking and research related to consumer assessments of care. The NCBD is sponsored by the Agency for Healthcare Research and Quality (AHRQ) and administered by Westat and Shaller Consulting.

All sponsors of CAHPS® surveys that are administered according to CAHPS® specifications are invited to participate in the NCBD. Survey sponsors include public and private purchasers (employers, State Medicaid agencies, and Medicare) and individual health plans. The NCBD includes two major data sets:

- 1. <u>CAHPS® Survey Response Data</u>: The core of the NCBD is composed of CAHPS® survey data, submitted at the individual respondent level by participating sponsors according to specifications provided by the NCBD project. These data include all information from the CAHPS® survey, except for information identifying respondent names, addresses, telephone numbers, and member ID numbers. *The NCBD includes no data identifying individual respondents.* Certain survey administration data, such as mode of administration and survey language, and descriptive information such as state or zip code of residence, may also be included in this data set.
- 2. <u>Survey Administration and Health Plan/Provider Characteristics Data</u>: This data set includes information regarding survey administration, such as mode of administration, response rates, and dates of survey completion. Descriptive information relating to each of the sampled units (e.g., health plan products or provider groups) is also included, such as type of organization, size of enrollment, tax status and ownership, and location.

Further information on the NCBD, including details on the current composition of the NCBD and the layout of the research files, can be obtained from the CAHPS Web site located at: https://www.cahps.ahrg.gov/content/ncbd/ncbd\_Intro.asp?p=105&s=5

## **Process for Requesting Data Files**

Researchers interested in obtaining data from the NCBD must submit:

- 1. A written proposal (including the contents specified below);
- 2. A signed data use agreement (available upon request); and
- 3. Institutional Review Board (IRB) approval of the proposed research project, or a justification of why IRB approval is not needed for the proposed research.<sup>1</sup>

All proposals are reviewed by the Executive Research Committee (ERC) of the NCBD Advisory Group, in accordance with the criteria outlined below. The review period for data requests (i.e., the time from receipt of request to notification of ERC decision) is typically 2 to 3 weeks.

<sup>&</sup>lt;sup>1</sup> Westat's IRB has determined that, in general, research activities undertaken with the NCBD are exempt from the requirements of Title 45, Part 46 of the Code of Federal Regulations (CFR), because no information identifying individuals is included with the data. This determination does not relieve researchers from obtaining their own human subjects clearance; however, they may cite this determination in their application for IRB review.

### **Proposal Contents**

Proposals should include the following information:

- 1. Title of the proposed research project.
- 2. Statement of the problem and the objectives of the proposed research.
- 3. Specific data files requested (e.g., commercial, Medicaid, adult, children, CAHPS® version, survey time period, etc.) and the specific substantive items that will be used in the analyses (e.g., respondent age, race/ethnicity, etc.);
- 4. Description of analytic methods.
- 5. Key personnel involved, time line for completion, and a description of the relevant experience of the study team.
- 6. A description of how the data will be stored and protected.

### **Proposal Review**

All requests for access to NCBD data files are reviewed and acted on by the ERC. Members of the ERC are appointed by the NCBD Advisory Group, and include representatives of the Agency for Healthcare Research and Quality (AHRQ), survey sponsors, and current CAHPS principal investigators. (A current list of ERC members is available upon request.) Access to data files must be approved by at least two-thirds of the ERC members voting in favor of the request. Members of the ERC may not participate in any review or action related to a data request of their own.

The purpose of the proposal review is not to critique the methodology or merits of the proposed project. The primary concern of the ERC is to determine that the proposed research does not compromise the confidentiality of individual survey respondents, survey sponsors, health plans, or provider groups. In regard to the identity of specific survey sponsors, health plans, or provider groups, the ERC will observe the following guidelines:

- Access to aggregate data files that do not identify individual sponsors, health plans, or provider
  groups by name may be granted by the ERC without the specific authorization of the sponsors,
  health plans, or provider groups whose data are included as part of the aggregate data files. These
  data files may include a variable describing the sponsor type (e.g., Medicaid, public employer, private
  employer, or health plan).
- Access to sponsor-specific and health plan or provider group-specific data files may be granted by the ERC only with the express written authorization of the sponsor, health plan, or provider group whose data files are requested. Analyses of the data files provided to researchers under these provisions may not be made public without the express written authorization of all sponsors, health plans, or provider groups who may be identified in the published analysis.

#### **Conditions for Denying a Proposal**

Requests for access to NCBD data files may be denied under any of the following conditions:

- 1. The proposed research may compromise the privacy or confidentiality of individual respondents.
- 2. The proposed research may reveal specific survey findings related to individual survey sponsors, health plans, or providers (without their express authorization).

- 3. The central purpose of the study is not research or evaluation.
- 4. The research objectives are not feasible using the requested data.
- 5. The data processing required to produce the requested data files places an unusually heavy burden on NCBD data processing staff. (Note: It may be possible to respond to a burdensome request if the requestor is able to pay for the effort required.)

If there are concerns about a proposal raised during the review process, the comments of the reviewers will be sent to the requestor. Investigators may make modifications and re-submit the proposal for review. The ERC will also advise the requestor of the same or similar projects that may be underway, to avoid duplication of effort and to encourage collaboration where possible.

# **Publication Requirements**

Researchers receiving NCBD data are required to include the following acknowledgment in any publication or presentation using NCBD data:

"The CAHPS® data used in this analysis was provided by the National CAHPS® Benchmarking Database (NCBD). The NCBD is funded by the U.S. Agency for Healthcare Research and Quality and administered by Westat under Contract No. 290-01-0003."

Copies of all publications and presentations using NCBD data must be sent to the NCBD. The NCBD will issue periodic updates on its Web site and in other publications regarding the current status of approved research projects. These updates may include contact information for the principal investigator.

#### **Disclaimer**

Approval of data access does not constitute endorsement by the NCBD of the proposed research project, study findings, or recommendations of the research team.

#### **Contact Information**

Questions regarding the NCBD and this Data Release Policy should be directed to Dale Shaller, NCBD Managing Director, by e-mail at <a href="mailto:d.shaller@comcast.net">d.shaller@comcast.net</a> or by phone at 651-430-0759. Proposals for data access should be sent to:

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